



COMMONWEALTH of VIRGINIA

Department for the Aging

Jay W. DeBoer, J.D., Commissioner

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1610 Forest Avenue, Suite 100, Richmond, Virginia 23229

Toll-Free: 1-800-552-3402 (Voice/TTY) • Phone: 804-662-9333 • Fax: 804-662-9354

E-mail: aging@vda.virginia.gov • Web Site: www.vda.virginia.gov

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Janet Dingle Brown, Guardianship & Legal Services Development Coordinator

DATE: August 9, 2005

SUBJECT: AoA Presentation - September 16, 2005
Legal Resources for Older Virginians: Where Do We Stand?

The Virginia Elder Rights Coalition (VERC) has asked me to extend a special invitation for its September 16, 2005 meeting:

GUEST SPEAKER:

AoA - Brandt Chvirko, Special Assistant to the Assistant Secretary AoA, U.S. Dept. of Health & Human Services

TOPIC:

Dialogue & Discussion on Legal Resources for Older Virginians: Where Do We Stand?

DATE/TIME:

Friday September 16, 2005; 10:00 A.M. - 12:30 P.M.

LOCATION:

Senior Connections AAA
24 East Cary Street (Corner of Cary and 1st Street)
Richmond, VA 23219

All are invited.

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Ellen M. Nau, Human Services Program Coordinator

DATE: August 9, 2005

SUBJECT: User's Manual: Virginia Uniform Assessment Instrument (UAI)

The Revised User's Manual: Virginia Uniform Assessment Instrument (UAI) is now available on the Virginia Department for the Aging Website at <http://www.aging.state.va.us/UAI%20User%20Manual.pdf> Leonard Eshmont and Rochelle Clark (VDA's IT Department) have graciously highlighted changes in this July 2005 Revision. It is located in the service program area, service provider section of the VDA website.

Training for using the Virginia Uniform Assessment Instrument is now available through VISSTA (Virginia Institute for Social Service Training Activities). Sessions will be held at the following locations:

9/8/2005	Fairfax	Pennino Bldg.	ADS5011
11/14/2005	Roanoke	VISSTA Roanoke Area Training Center	ADS5011

For further information contact:
VISSTA
104 North Linden Street
P.O. Box 842027
Richmond, VA 23284-2027
Office: (804) 828-0178/Fax: (804) 828-1207
Email: vista@vcu.edu

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: Tim M. Catherman
Deputy Commissioner, Support Services

DATE: August 9, 2005

SUBJECT: Virginia Aging and AoA in the News

Below are Virginia Aging or AoA related articles that have occurred since last week's Tuesday E-mailing. These links do not require a paid service; however, some (like the Washington Post, etc.) ask a brief survey or registration. Please note some links are time sensitive and can change daily. Some articles may be editorial and/or political. Links are presented 'as is'.

If you are aware of additional articles, please e-mail me a link for inclusion next week.

Virginia AAAs In the News

[Medicare drugs](#)

Richmond Times Dispatch - Richmond, VA

... Social Security workers, Medicare, Medicaid, aging agencies and volunteers in the Virginia Insurance Counseling and Assistance Program (VICAP), among others ...

[Nursing center denied payment](#)

Charlottesville Daily Progress - Charlottesville, VA

... are working very closely with the state of Virginia to follow ... similar stressed situation," according to Joani Latimer, the long-term care ombudsman for the ...

[Greene to get free care clinic](#)

Charlottesville Daily Progress - Charlottesville, VA

... The clinic is starting small, with evening hours four nights a week at the Jefferson Area Board for Aging center in Stanardsville. ...

Virginia Aging and AoA in the News

Page 2 of 2

[Trying to beat the heat](#)

Prince George's Journal - Rockville, MD

... a partnership between Dominion Virginia Power and the Virginia Department for ... conditioning," said Terri Lynch, director of the Arlington Area Agency on Aging. ...

[Va. Nursing Homes' Settlements Hidden](#)

The Washington Post

In April 2004, the U.S. attorney's office for eastern Virginia agreed to what it calls an innovative settlement with a 177-

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Directors,
Area Agencies on Aging

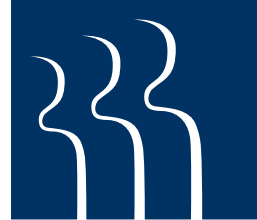
FROM: Bill Peterson,
Deputy Commissioner for Programs

DATE: August 9, 2005

SUBJECT: Caregiving and Paid Work

Attached is the fourth in a series of Data Profiles on informal caregivers of older persons titled *Caregiving and Paid Work - Are There Trade-Offs?* from the Center on an Aging Society at Georgetown University.

Attachment



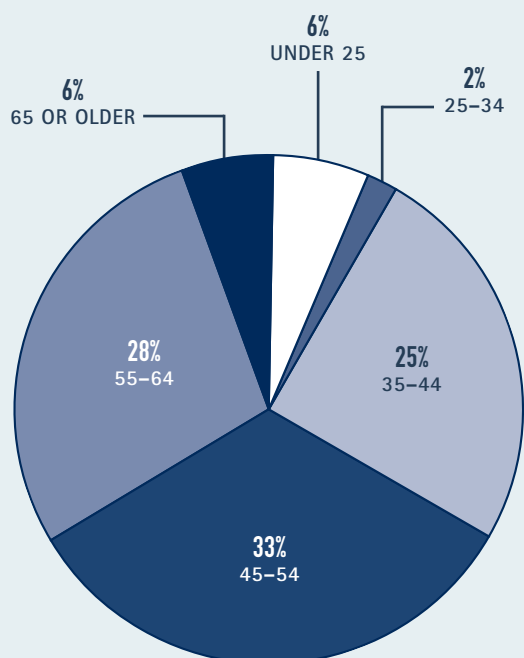
Center on an Aging Society
GEORGETOWN UNIVERSITY

Caregiving and Paid Work

Are there trade-offs?

Nearly one-third — 32 percent — of all primary family caregivers, regardless of age, are in the labor force.¹ About 6 percent of working caregivers are age 65 or older while the majority — 88 percent — are between the ages of 25 and 64 (see Figure 1). Among primary caregivers of working-age, more than half — 58 percent — are employed and most of those employed (83 percent) are working full time (35 or more hours per week).

FIGURE 1
Age Distribution of Primary Working Caregivers, 1999



SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long term Care Survey (NLTCs).

This *Data Profile* examines primary family caregivers age 25 to 64 who are working and those who are not working. Primary caregivers are family members, friends or volunteers who coordinate and provide the majority of the care to those who are age 65 or older and need long-term care. Long-term care is the need for assistance performing Instrumental Activities of Daily Living (IADLs), such as doing housework, managing medication or finances, or transportation, and/or Activities of Daily Living (ADLs) such as eating, bathing, dressing, using the toilet, or moving about. Moreover, “working” or “employed” refers to any primary caregiver that receives employment compensation, and the term “working-age” refers to primary caregivers age 25 to 64.

Characteristics of primary caregivers who are working compared to those not working

Non-working caregivers are more likely to be married women living with and providing care to their spouse (see Table 1).

TABLE 1

Demographic Characteristics of Working Caregivers versus Non-Working Caregivers (Age 25–64), 1999

	WORKING	NON-WORKING
GENDER		
Male	26%	16%
Female	74%	84%
MARITAL STATUS		
Married	50%	65%
Widowed	5%	4%
Divorced	18%	14%
Separated	2%	3%
Never Married	23%	13%
Partnered, Not Married	1%	1%
RELATIONSHIP TO THE CARE RECIPIENT		
Spouse	4%	14%
Son/Daughter (–in-law)	77%	70%
Parent (–in-law)	0%	1%
Sibling (–in-law)	1%	1%
Other Relative	11%	10%
Non-Relative	6%	4%
HEALTH STATUS		
Excellent	34%	20%
Good	48%	36%
Fair	17%	32%
Poor	1%	12%
LIVING ARRANGEMENT		
Living with the Care Recipient	43%	60%

SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCs).

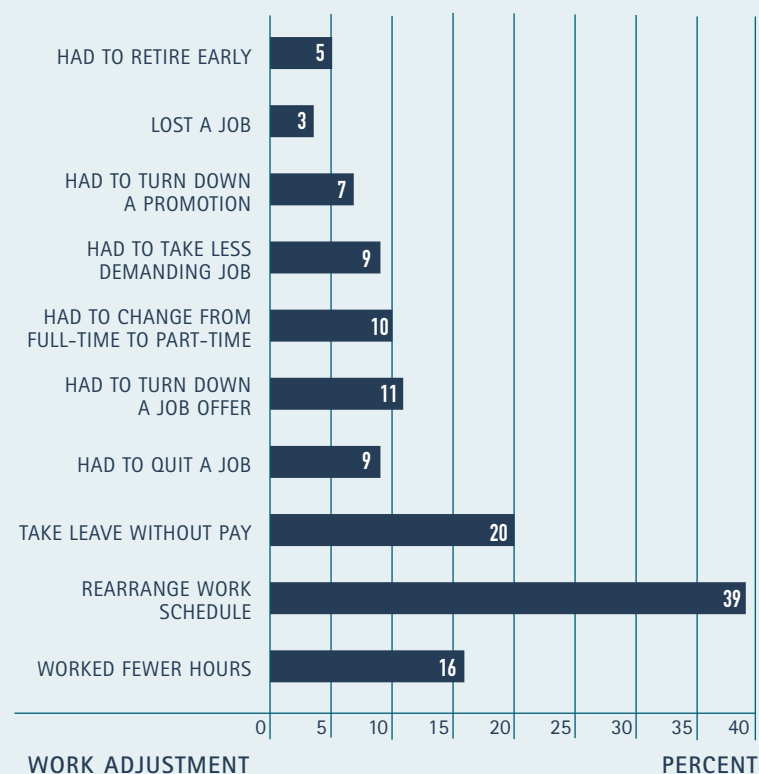
Working caregivers are more likely to be male, unmarried, adult children that do not live with the care recipient. About one in four working caregivers were male compared to 16 percent of non-working caregivers. More than two-thirds of non-working caregivers and half of working caregivers were married. While nearly two thirds of non-working caregivers lived with the care recipient, less than half – 47 percent – of working caregivers did. Working caregivers are much more likely to say they are in good or excellent health while non-working caregivers are more likely to say they are in fair or poor health.

Work adjustments are not uncommon

It is not uncommon for workers to make adjustments to their schedule when they are also primary caregivers (see Figure 2). Among those who have ever worked while providing care (includes both currently working caregivers and caregivers who are no longer working but have worked while caregiving), 39 percent rearranged their work schedule. Others have worked fewer hours in order to provide care or have taken time off without pay – 16 and 20 percent, respectively. Among caregivers not currently working, a substantial proportion – 56 percent – stopped working while they were a primary caregiver and 17 percent reported that they stopped working to provide care to the care recipient.²

FIGURE 2

Proportion of Working Caregivers (Age 25–64) that Made Work Adjustments by Type of Adjustment, 1999



SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCs).

NOTE: "Working Caregivers" includes both currently working caregivers and caregivers who are no longer working but have worked while caregiving.

Some working caregivers hesitate to tell their supervisor about their caregiving responsibilities

Some working caregivers may hesitate telling their employer about their caregiving responsibilities. Some 16 percent of working caregivers have not told their employer about their caregiving responsibilities. However, over half – 57 percent – of caregivers feel that their employer is

TABLE 2

Proportion of Working Caregivers (Age 25–64) Agreeing or Disagreeing to Statements about the Past Two Months, 1999

	PERCENT (%)
I HAVE LESS ENERGY FOR WORK	
Strongly Disagree	32
Disagree	44
Somewhat Agree	17
Agree	6
I MISSED TOO MANY DAYS OF WORK	
Strongly Disagree	46
Disagree	45
Somewhat Agree	6
Agree	4
I AM DISSATISFIED WITH THE QUALITY OF MY WORK	
Strongly Disagree	44
Disagree	44
Somewhat Agree	9
Agree	3
I AM WORRIED ABOUT THE CARE RECIPIENT WHILE I AM AT WORK	
Strongly Disagree	25
Disagree	31
Somewhat Agree	30
Agree	14
I HAVE BEEN INTERRUPTED BY TELEPHONE CALLS ABOUT/FROM THE CARE RECIPIENT WHILE AT WORK	
Strongly Disagree	42
Disagree	40
Somewhat Agree	13
Agree	5

SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCs).

EMPLOYERS LOSE AS A RESULT OF LOST PRODUCTIVITY

Employers report that caregiving affects worker productivity by increasing employee absenteeism, turnover, and early retirement. In 1997, Metropolitan Life Insurance Company (MetLife) estimated that working caregivers cost businesses roughly \$11.4 billion per year.⁶ If additional health care costs associated with the stress of caregiving were included, the estimated cost to employers could be as high as \$29 billion per year.

This has encouraged companies to offer work-based caregiver support programs. Between 1993 and 1999 caregiver support programs more than doubled among Fortune 100 and Fortune 500 companies, increasing from 20 percent in 1993 to 47 percent in 1999.⁷ Nearly one in four – 23 percent – of companies with 100 or more employees have resource and referral programs in place to support caregivers, 9 percent offer long-term care insurance and 5 percent provide direct financial contributions to elder care programs in the communities in which they operate.⁸ Other work-based caregiver support programs include employer-sponsored seminars and fairs about caregiving and long-term care, support groups, providing employees with geriatric care managers, respite care services, flexible spending/dependent care accounts, flexible schedule options, or in-kind cash contributions to support caregiver programs and services. However, only a third of working caregivers knew about their company's caregiver programs despite the fact that the programs in place were comprehensive and available to all employees.⁹ Employers need to make a concerted effort to inform their employees of their caregiving benefit options.

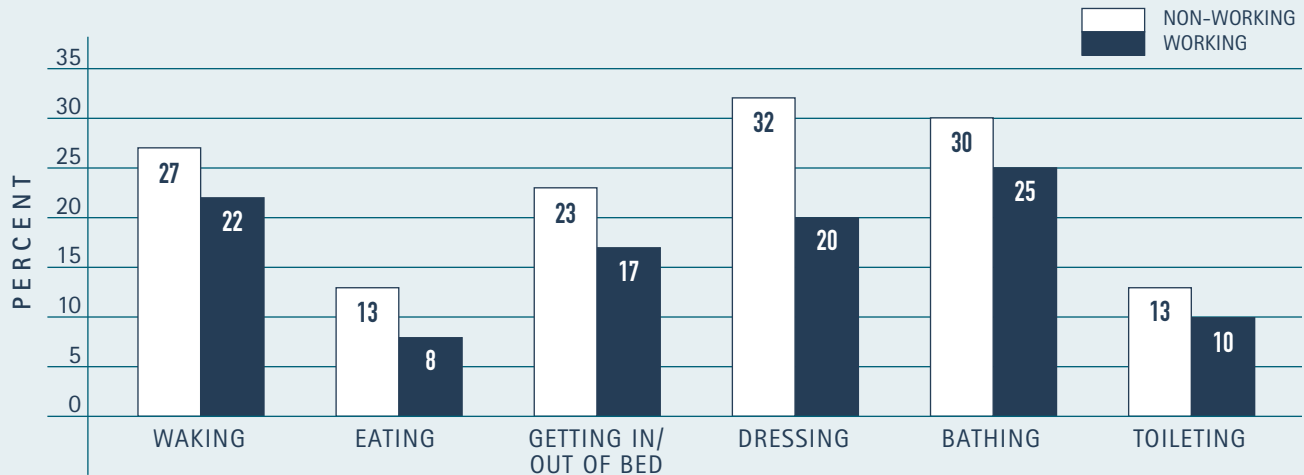
very understanding of their caregiving demands.³ A minority – 24 percent – of caregivers said their employer is only somewhat understanding and 3 percent reported that their employer is not very understanding.⁴

Caregiving may affect work productivity

Caregiving may also affect one's performance at work (see Table 2). Overall, 44 percent of working caregivers have had a conflict between their job and caregiving responsibilities.⁵ Over one-third of working caregivers acknowledge spending time during the work day worrying about their loved one. Nearly a quarter – 23 percent – of working caregivers acknowledge that they have had less energy at work in the past two months. Few working caregivers – 10

FIGURE 3

Proportion of Working Caregivers and Non-Working Caregivers (Age 25–64) by Type of ADL Help Provided, 1999



SOURCE: Center on an Aging Society's analysis of data from the *Informal Caregiver Supplement* (ICS) to the 1999 National Long Term Care Survey (NLTCS).

percent – report having to miss days of work to provide care and one in ten caregivers – 12 percent – report that they are dissatisfied with the quality of their work as a consequence of their caregiving responsibilities. Roughly 18 percent of caregivers are interrupted at work by telephone calls about or from the care recipient.

Working caregivers are better-off financially than non-working caregivers

Similar proportions – 20 percent – of working and non-working caregivers report feeling that the cost of providing care is more than they can afford. Non-workers, however, experience more overall financial strain and have lower incomes than working caregivers. Nearly one in four – 24 percent – of non-working caregivers report feeling financially strained while 19 percent of working caregivers did. Approximately 41 percent of non-working caregivers had annual household incomes below \$25,000 compared to 23 percent of working caregivers.¹⁰ One study estimated that women who reduced their hours to provide care to a parent or parent-in-law gave up an average of \$7,800 in pre-tax wages in 1994 (which was about 20 percent of median family income among these women).¹¹

Working caregivers provide fewer hours of care

Clearly, workers face more competition for their time than non-workers. The median hours of care provided per week by working caregivers is half that provided by non-working caregivers – 10 and 20 hours, respectively.¹² However, working caregivers are more likely to have a helper if needed to provide extra care. Over two-thirds – 67 percent – of working primary caregivers say that if they were unable to help the care recipient that they had a secondary helper lined-up who could. Among non-working primary caregivers, 54 percent had a helper if they could not provide needed care.

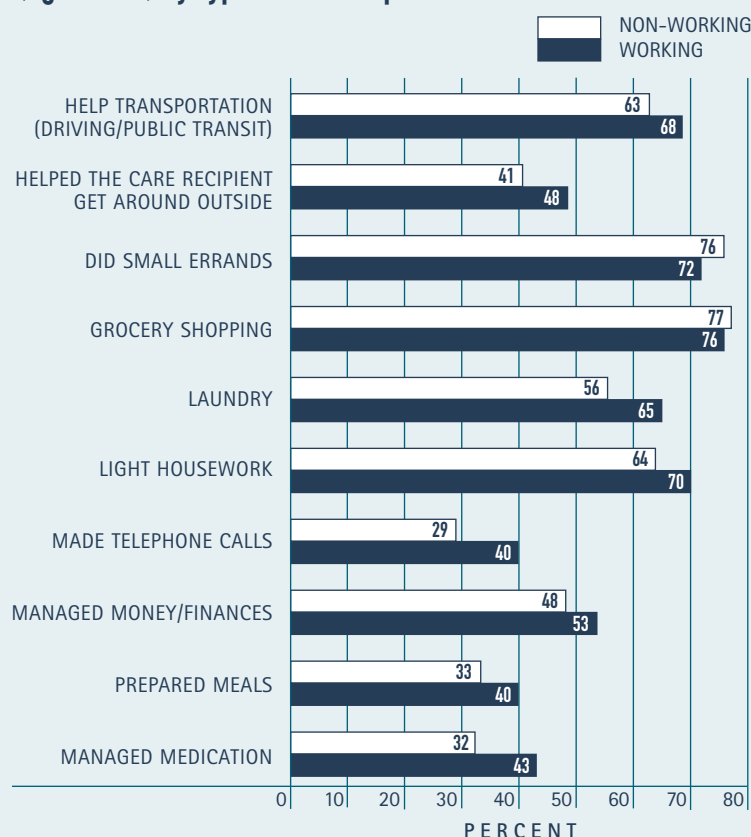
Workers provide less ADL help than non-workers

A smaller proportion of working caregivers provide help with Activities of Daily Living (ADLs) compared to non-working caregivers – 37 percent and 49 percent, respectively. Differences in the proportions of working and non-working caregivers providing help with dressing and getting in and out of bed are the most substantial (See Figure 3).

Similar proportions of workers and non-workers provide help with Instrumental Activities of Daily Living (IADLs) includ-

FIGURE 4

Proportion of Working Caregivers and Non-Working Caregivers (Age 25–64) by Type of IADL Help Provided, 1999



SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCS).

ing money management, grocery shopping, and providing transportation. Non-working caregivers are more likely, however, to administer medications or medical care, make telephone calls, and do housework including laundry (see Figure 4).

Use of formal services is more common among workers

Working caregivers are somewhat more likely to use caregiver supportive services than non-working caregivers. For example, one-tenth of working caregivers have used a respite service, compared to some 7 percent of non-working caregivers. And, the proportion of working caregivers attending a support group is double that of non-working caregivers. Compared to non-working caregivers, somewhat larger proportions of working caregivers use formal care services to help provide needed care. The most substantial difference is

the use of a home modification service. Some 28 percent of those who are working compared to 18 percent of those who are not working have used a service to modify the care recipient's home (See Table 3). And, a larger proportion of working caregivers compared to non-working caregivers have obtained assistive devices for the care recipient – some 54 and 47 percent, respectively.

TABLE 3

Proportion of Working Caregivers and Non-Working Caregivers (Age 25–64) That Report Using Specific Caregiver Support Services, 1999

TYPE OF CAREGIVER SUPPORT SERVICE	WORKING	NON-WORKING
Received any respite or caregiver support from a government source	12%	9%
Requested information about how to get help	12%	16%
Has taken part in a support group of caregivers	10%	5%
Used a service to temporarily take care of the care recipient to get some time away	7%	8%
Enrolled the care recipient in a program outside the home such as an Adult Day Care or senior center	5%	4%
Had a service come to help with personal care or nursing care at the care recipient's home	33%	35%
Had a service come to help you with housework at the care recipient's home	15%	9%
Had an outside service deliver meals to the care recipient's home	11%	16%
Had an outside service provide transportation for the care recipient	12%	14%
Had any home modifications made to the care recipient's home to make things easier	25%	20%
Obtained assistive devices, such as wheelchairs, walkers, etc., for the care recipient	47%	44%

SOURCE: Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCS).

ABOUT THE DATA

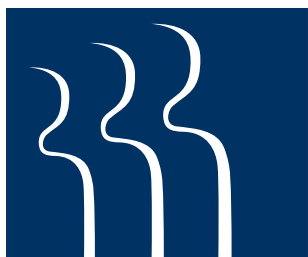
Unless otherwise noted, data in this *Profile* are from the 1999 National Long Term Care Survey (NLTCS). The NLTCS is sponsored by the U.S. Department of Health and Human Services and conducted by the Center for Demographic Studies at Duke University. The Caregiver Supplement to the NLTCS collects data on the experiences of the primary informal caregivers of the disabled population age 65 and older living in the community.

1. Center on an Aging Society's analysis of data from the *Informal Caregiver Supplement* to the 1999 National Long Term Care Survey.
2. Ibid.
3. Ibid.
4. MetLife Mature Market Group & National Alliance for Caregiving (NAC) (1997) *The MetLife Study of Employer Costs for Working Caregivers* (NY: Metropolitan Life Insurance Company). The estimated costs to businesses includes the costs associated with replacing employees, absenteeism, partial absenteeism, workday interruptions, elder care crises, and supervisor's time spent providing support, counseling, arranging coverage for absent or late employees, and dealing with work disruptions.
5. Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCS).
6. MetLife Mature Market Group & National Alliance for Caregiving (NAC) (1997) *The MetLife Study of Employer Costs for Working Caregivers* (NY: Metropolitan Life Insurance Company)



Center on an Aging Society

GEORGETOWN UNIVERSITY



2233 Wisconsin Avenue NW
Suite 525
Washington, DC 20007

TEL 202.687.9840
FAX 202.687.3110

WEBSITE www.aging-society.org

ABOUT THE PROFILES

This is the fourth in a series of *Data Profiles*, *Family Caregivers of Older Persons*. The series is supported by a grant from AARP and Mather-Lifeways. This *Profile* was written by Katherine Mack with assistance from Robert Friedland.

The Center on an Aging Society is a Washington-based non-partisan policy group located at Georgetown University's Health Policy Institute. The Center studies the impact of demographic changes on public and private institutions and on the economic and health security of families and people of all ages.

7. Piktialis, D. S. (2001) *Forging Relationships with Business* National Family Caregiver Support Program: From Enactment to Action Conference Issue Brief (Washington, DC: Administration on Aging), http://www.aoa.gov/prof/aoaprof/caregiver/careprof/proguidance/background/program_issues/Fin-Piktialis.pdf.
8. Families and Work Institute (1998) *Business Work-Life Study: Investigating how US employers are responding to work-life needs (Executive Summary)* (NY: Families and Work Institute)
9. MetLife Mature Market Institute (2003) *The MetLife Study of Sons at Work Balancing Employment and Eldercare: Findings from a National Study by the National Alliance of Caregiving and The Center for Productive Aging at Towson University* (NY: MetLife).
10. Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCS). A substantial proportion – 27 percent – of respondents' household income data were missing and excluded from the data used to calculate the distribution of caregivers by income and employment status.
11. Johnson, R. & Lo Sasso, A. (2000) *The Trade-Off Between Hours of Paid Employment and Time Assistance to Elderly Parents at Midlife* (Washington, DC: The Urban Institute)
12. Center on an Aging Society's analysis of data from the Informal Caregiver Supplement (ICS) to the 1999 National Long Term Care Survey (NLTCS)

DATA PROFILES ARE AVAILABLE ON LINE

SIGN UP FOR EMAIL ALERTS AT
WWW.AGING-SOCIETY.ORG

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors
Area Agencies on Aging

FROM: E. Janet Riddick, Director
Center for Elder Rights

DATE: August 09, 2005

SUBJECT: Olmstead - Invitation for Public Comment

The Virginia Olmstead Initiative, Community Integration Oversight Advisory Committee is requesting public comments on two draft documents. The documents will be incorporated into the Advisory Committee's 2005 report to Governor Warner. Please see the attached invitation to comment and the two draft documents. Comments must be received by September 05, 2005. Thank you.

THE OLMSTEAD INITIATIVE
Community Integration Oversight Advisory Committee

DRAFT COMMUNITY INTEGRATION PRIORITIES FOR 2005

Please Note: *The Committee has adopted five (5) top community integration priorities and is considering presenting these five and nine (9) additional recommendations in its October 2005 report to Governor Warner. The 14 recommendations are those that we believe are most essential to support adequate and appropriate infrastructure of community-based services, and are needed either to move people from institutions to the community or to prevent unnecessary or unwanted institutionalization.*

The 14 recommendations appear below, organized within three major categories: Community Infrastructure, Increased access to services and supports by those currently eligible for them, and Increased access to services and supports by those not currently eligible for them. The Committee's top five priorities are indicated immediately preceding the recommendations to which they apply.

Thank you very much for your comments.

I. COMMUNITY INFRASTRUCTURE

A. Priority #1: Increase all Medicaid reimbursement rates to include the maximum allowable cost of service; automatic cost of living adjustments (COLA); geographical rate differentials; travel and transportation; staff training and supervision; and inflation.

- ✓ Ensure that caregiver pay rates are reflected.
- ✓ Reimburse Direct Support Professionals (DSPs) at higher pay and benefits for certifications and career enhancement.
- ✓ Increase Medicaid reimbursement rates for transportation services to adequately cover the cost of operations.

B. Priority #3: Continue to fund and develop community services to **eliminate the State mental health facility discharge waiting lists.**

C. Priority #4: Develop and fully fund **incentives to attract and retain qualified candidates to disability fields of care:**

- ✓ Develop a larger skilled professional staff pool by aggressive recruitment and training efforts.
- ✓ Increase the available pool of providers by re-titling Direct Care workers, paraprofessionals, and others to "Direct Support Professionals." Ensure that regulations and training materials use that title.
- ✓ Provide information and documents to DSP employers to help them make DSPs aware of, and help them apply for, State and Federal programs and benefits for which they may be eligible.

D. Develop funding, fiscal and other incentives for providing and establishing new services, including employment and quality integrated community-based day support Medicaid-funded services.

E. Include employment as an issue in discharge planning protocols for individuals wishing to work in the community.

F. Promote recovery-oriented services designed to prevent institutionalization for adults with serious mental illness, including effective consumer-operated and peer services. Develop a **mental health consumer group to mentor** those seeking transitions.

II. INCREASED ACCESS TO SERVICES AND SUPPORTS BY THOSE WHO ARE CURRENTLY ELIGIBLE FOR THEM

A. Priority #2: Increase the availability of funded Medicaid Waiver slots. Continue to eliminate waiting lists for Waivers and other supportive services; avoid future waiting lists by anticipating regular increases in need for services. Fund 25% of 2003 waiting list in 2005; 45% of 2004 waiting list in 2006; 65% of 2005 waiting list in 2007; 80% of 2006 waiting list in 2008; and 100% of waiting list, except those waiting 90 days or less, in 2009. Require DMAS to include on the urgent waiting list people in nursing facilities and Intermediate Care Facilities for the Mentally Retarded (ICFs/MR) who are ready for discharge and who want to move. The number of slots to be allocated as "institutional" slots would be determined according to the following formula:

- ✓ Add the number of people in nursing facilities and ICFs/MR who are discharge ready, and who want to move, to the number of people on the Urgent list, making sure they are not counted twice.
- ✓ When new slots are allocated, base the percentage of slots allocated to people in institutions on the percentage of people who meet the above criteria, when compared to the total percentage of people on the Urgent list.

For example, if people in institutions constitute 10% of the total list, then 10% of any new slots would be allocated for people in institutions.

B. Increase the personal maintenance allowance (PMA) to 300% of the monthly SSI payment limit in all Waivers. Currently, the state allows an individual to retain \$579 to pay rent, utilities, food, clothing, and other expenses. The Joint Commission on Healthcare has twice recommended that the PMA be increased to a more realistic level.

C. Establish and grant emergency regulatory authority for a revolving fund for people in institutions to use for utility and rent deposits and other upfront household expenses to enable them to move from institutions.

D. Amend Va. Code § 54.1-3000 and other relevant sections (commonly known as the “Nurse Practices Act”) and associated regulations to exclude personal assistants, respite workers and companion aides under direction of a consumer or his/her surrogate from the requirements of the Act. Model the amendment on provisions in the Kansas statute that permit attendants to provide activities if the activities may be performed by the individual if the individual were physically capable, and the procedure may be safely performed in the home.

**III. ACCESS TO SERVICES AND SUPPORTS BY THOSE WHO ARE
NOT CURRENTLY ELIGIBLE FOR THEM:**

A. *Priority # 5:* Increase Medicaid financial eligibility to 100% of federal poverty level.

B. Fund the **Brain Injury Waiver.**

C. Implement the **Dementia Waiver.**

D. Assure that State level **consolidated and housing agency plans identify persons with disabilities as a high priority housing need population. Mandate agencies, in allocating Section 8 voucher assistance, grant funds and low- and no-interest loans and technical assistance to assign high priority to these needs.**

THE OLMSTEAD INITIATIVE
Community Integration Oversight Advisory Committee

**Executive Order 84 Recommendations as Presented by the
Olmstead Initiative Implementation Team**

Please Note: *Executive Order 84 directed that the state agency Implementation Team make six specific recommendations to the Committee, and that the Committee make six specific recommendations to the Governor. The Second Annual Implementation Team Report, issued July 15, 2005, contained the Team's recommendations, which appear in their entirety below. The Committee is now considering these recommendations and will formulate its own recommendations for inclusion in the Committee's October report.*

Thank you very much for your comments.

1. Increasing membership of people with disabilities, family members, and surrogate decision-makers on state and local boards and commissions

Relevant state agencies could contribute to the preparation of a comprehensive packet of information that would be distributed to all state and local government entities in the Commonwealth to assure the availability of consistent resource materials. The packet could be assembled and distributed by the Office of Community Integration for People with Disabilities (OCI) and include information about:

- The ADA [Americans with Disabilities Act];
- The *Olmstead Initiative*;
- Why it is important to involve people with disabilities;
- What has already been done to increase participation;
- How to locate and use meeting accessibility and accommodations guidance documents;
- How to locate and recruit qualified people with disabilities;
- Website addresses with further resources; and
- Disability etiquette.

People with disabilities need to be aware of programs and resources available to assist them in preparing to serve.

- Disability Services Boards (DSBs), CILs [Centers for Independent Living], CSBs [Community Services Boards], and other consumer advocacy groups could serve as a resource for ongoing information for people with disabilities who would like to serve on work groups, task forces, boards and commissions;
- Programs such as DMHMRSAS' CELT [the Department of Mental Health, Mental Retardation and Substance Abuse Services' Consumer Empowerment and Leadership Training] could be more widely advertised and expanded, as

appropriate, and VBPD's [the Virginia Board for People with Disabilities'] Partners in Policy-Making could be more widely advertised so that more people would be aware of the opportunities these programs offer; and

- Agencies could earmark a modest amount of funding for travel reimbursement and related expenses that would otherwise deter or prevent a person with a disability from participating as a member of work groups, task forces, boards and commissions.

At the state level, ADA Coordinators or other designated persons within all state agencies could be responsible for:

- Maintaining lists of agency work groups, agency task forces, and gubernatorial boards and commissions related to that agency;
- Actively seeking out and maintaining a list of people with disabilities interested in serving on these work groups, agency task forces, and gubernatorial boards and commissions;
- Helping to match people with disabilities to other agencies' work groups and task forces;
- Consulting with disability services agencies when they lack names of qualified candidates; and
- Providing a link on each agency's website and/or intranet to the accessibility considerations and meeting planner guidelines currently on the *Olmstead* website.

ADA Coordinators or other designated persons at state agencies responsible for providing services to people with disabilities could assist other state and local agencies that may be less familiar with these issues in the following areas:

- Naming and training an ADA coordinator;
- For small agencies not required to have an ADA Coordinator, how to accomplish the same goals; and
- Making local agency ADA Coordinators aware of both their responsibilities and the resources available to them on an ongoing basis.

2. Establishing and maintaining a list of residents, by disability, who are appropriate for discharge, who want to be discharged, from nursing facilities and assisted living facilities

Nursing Facilities:

As discussed [elsewhere in] this report, VBPD recently awarded a grant to VACIL [the Virginia Association of Centers for Independent Living] to inform people with disabilities who reside in nursing homes about community living options and supports, identify individuals who may be interested in moving into more integrated settings, and as feasible, assisting a limited number of individuals to transition to a more integrated setting. VACIL will work with state and other agencies already involved in nursing home transition issues. This grant will serve to begin identifying people who wish to leave nursing facilities over the next 18 months as a bridge to the following.

DMAS [the Department of Medicaid Assistance Services] could work to develop a user agreement with CMS [the Center for Medicare and Medicaid Services] for Minimum Data Set (MDS) data relating to residents' desire to return to the community. DMAS could explore appropriate means of sharing relevant MDS data with the VBPD, so that VBPD could communicate the information to VACIL, and VACIL could use the data to help focus its grant efforts.

Nursing Facilities and Assisted Living Facilities:

- Secure legislation and funding to:
 - ✓ Mandate visits with nursing and ALF [Assisted Living Facility] residents within 3 months of admission and every year thereafter to explore options for community living;
 - ✓ Give, and expand the availability of, options to those who currently live in nursing and ALFs; and
 - ✓ Implement a Statewide case management system;
- Begin to develop a waiting list based on face-to-face contacts with people who show an interest in living in the community. Because DMHMRSAS has managed a waiting list for MH [mental health] facility residents for several years, experts from that Department would be consulted in the development and monitoring of the waiting list; and
- Review existing assessment instruments, procedures and training to encourage consideration of the most integrated settings and policies to incorporate choice.

As a supplement to the above activities, a 1-800 number could be developed for people who would like to leave ALFs or nursing facilities to live in a more integrated setting and information on how to access information in community living options could be posted in all nursing facilities and ALFs similar to the currently required Ombudsman information. The OCI could coordinate this service.

3. Assuring an appropriate statewide system for reporting of allegations of abuse, neglect, serious injuries and deaths by providers of community services and supports to people with disabilities

A statewide system could be developed. All current agency-based reporting requirements could first be identified and assessed. The assessment would include what must be reported in each case (abuse, neglect, injury, death, etc.), and to whom and by whom the report must be made. Compliance with current reporting requirements could also be assessed. Reporting gaps could then be identified, including providers not currently required to report; discrepancies in what must be reported to whom and at what level; non-compliances with current reporting requirements; and disability populations, if any, not currently covered by an appropriate reporting mechanism. Reporting gaps could be addressed through appropriate legislation, regulations, and/or administrative actions. Serious injury and death reports could be maintained by the agency having responsibility for receiving them.

4. Developing a statewide system of consistent rights notification that includes a means by which the quality of information given to [people with disabilities], and the consistency with which information is given, are tracked

The OCI, with the cooperation of all agencies represented on the Team and the advice and consultation of the Committee, could develop one consistent communication regarding community integration, such as that provided by the Office of the Attorney General and currently on the *Olmstead* website. Such a communication would serve as the basis for a document to inform people of the *Olmstead* decision, the state's role in community integration and the choices available to individuals with disabilities. The communication could be widely distributed in appropriate ways to individuals with disabilities, family members and surrogate decision-makers, and would be given to nursing facility and ALF residents within three (3) months of admission and annually thereafter in conjunction with the recommendation in number 2 above.

5. Monitoring the quality and coordination of services provided to persons with disabilities, including a process by which complaints relating to the denial, quality and coordination of services provided to persons with disabilities may be made by or on behalf of individuals with disabilities and resolved

Some states, for example West Virginia, have an *Olmstead* complaint process in place. Continuing research into what other states have done in this area, and specifically how existing complaint processes are being used to further community integration and increase coordination among agencies, would be helpful. Based on results of this research, the Commonwealth may wish to establish a process, possibly within the OCI, whereby individuals could file complaints related to community integration issues.

The Team believes the following to be necessary components of such a complaint process:

- Complaints would be limited to those relating to the desire of individuals with a disability to move to, live in, or stay in the most integrated setting appropriate to their needs, and:
 - ✓ Unsuccessfully resolved under existing agency processes; or
 - ✓ Not falling under the jurisdiction of any one particular agency.
- The complaint process would not replace or change any existing agency complaint processes. All existing agency complaint processes would remain intact and, if available, would have to be exhausted before a complaint could be filed.
- The office handling the complaints would have the authority to determine on a case-by-case basis whether or not a particular complaint is appropriate for consideration.
- There would be no authority to overturn any agency decision. The purpose of the process would be to assist the complainant and agency or agencies to reach a satisfactory resolution through mediation.

6. Developing a coordinated reporting system across agencies to monitor the effectiveness of efforts to improve the quality and coordination of services provided to persons with disabilities consistent with the ADA and recommendations in the Task Force Report, including a system to measure and evaluate the performance of the Commonwealth

Working with agencies represented on the Team, the OCI could develop a web-based reporting system for information regarding implementation of Task Force Report recommendations. This database would feature password security, and agencies would be able to log in and enter information related to specific recommendations they are tracking. Examples of information to be submitted would include: any action taken toward implementation of a recommendation, its outcome or predicted outcome, agencies and stakeholders involved in the process, follow-up action/s to be taken, and related costs. The OCI could monitor the data provided by the agencies and analyze it to determine progress toward implementation of Task Force Report recommendations and evaluate the Commonwealth's performance.

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Directors,
Area Agencies on Aging

FROM: Bill Peterson,
Deputy Commissioner for Programs

DATE: August 9, 2005

SUBJECT: Virginia's Delegation to the White House Conference on Aging

Attached is an updated list of Virginia's delegation to the 2005 White House Conference on Aging (WHCoA). For more information on the conference go to www.whcoa.gov.

The Commonwealth Council on Aging has invited Virginia's WHCoA delegation to join them for a joint session on Thursday, September 8, 2005 from 1PM until 4PM. This meeting will be held in the conference room of the Virginia Department of Rehabilitative Services. The purpose of this joint meeting is two-fold: first, to provide an opportunity for delegates to meet each other and the members of the Council and second, to provide a forum to discuss the critical aging issues facing the nation.

AAA directors are welcome to participate in this joint session but space will be limited so please RSVP by contacting Marsha Mucha at 804-662-9312 by Friday, August 26th.

Attachment

Virginia's Delegation to the 2005 White House Conference on Aging

Alfred (Fred) C. Anderson

3115 Burnt Quarter Drive

Vinton, VA 24179

Phone: 540-890-1578

Email: annandfred@prodigy.net

Appointed by: Congressman Bob Goodlatte (R-6th)

Biographical Statement:

Fred Anderson is married to the former Ann Melinda Riley of Farmville. They have two children: Army Captain Alfred C. Anderson, Jr. and Ann Claudine Anderson. They also have two grandchildren. He is active in the following organizations: the Thrasher Memorial United Methodist Church; Vinton Masonic Lodge #204 – Treasurer; Vinton OES # 136 – Patron; Vinton Host Lions Club - Treasurer and past president; Vinton Dogwood Festival - past president; Sixth District Republican Committee – Chairman; Republican State Central Committee of Virginia - Executive Committee; Treasurers' Association of Virginia - past president and 1985 Treasurer of the Year; National Association County Treasurers & Finance Officers - past president and 1996 Treasurer of the Year; National Conference of Republican County Officials - past president; National Association of Counties - Finance & Intergovernmental Committee - past chairman and Homeland Security Task Force.

Catherine C. Colgan

1500 Ashley Drive

Virginia Beach, VA 23454-1611

Phone: 757-496-9524

Email: John.colgan@gte.net

Appointed by: Senator John Warner

Biographical Statement:

U.S. Information Agency Foreign Service Officer - 1981-1988; "Voice of America" Broadcast Advisory Committee – 1989-92; U.S. Department of Defense "Defense Advisory Committee on Women in the Services (DACOWITS)" – 1988-91; U.S. Naval Academy Board of Visitors –1991-94; U.S. Air Force - 2005 National Security Forum; National Endowment for Democracy, International Republican Institute, Trainer (Romania) – 1996; Bush/Quayle Presidential Campaign, Chairman, Seniors For Bush National Coalition – 1988; Republican National Committee (RNC) –National Seniors Coalition, Vice Chairman – 1996; National Silver Haired Congress "Silver Senator" – 1996-2005; 2005 White House Conference on Aging; Virginia Board of Medical Assistance Services – 1997-2001; Commonwealth Council on Aging – 1999-2001;

Physicians For Peace, Trustee –1992-present; Medical Education Missions to Panama, Bahrain, the West Bank, the Czech Republic.

Ann M. Collins

NARFE

P. O. Box 2833

Springfield, VA. 22152-2833

Phone: 703-569-5224

Email: NARFE893@aol.com

Appointed by: Congressman Tom Davis (R-11th)

Biographical Statement:

- BBA Management Science, Chaminade University.
- Master of Public Administration, University of Oklahoma, 1985.
- Retired Federal civilian, 1999, with 33 years of service; since mainly a community volunteer and advocate for senior issues.
- Attended "Solutions Forum," Official Event of 2005 WHCOA, April 14, 2005, Williamsburg, VA.

Active participation with these organizations provides me with a good general knowledge of the grass roots concerns of Virginia's senior citizens:

- National Active and Retired Federal Employees Association (NARFE) - Currently President of Virginia Federation of Chapters (56 chapters with over 20,000 members); LIFE member and advocate to protect earned retirement benefits; Advocates jointly on common critical senior issues with AARP, Northern Virginia Aging Network, and other organizations on aging within Virginia.
- National Silvered Haired Congress - Appointed as Silver Representative, VA-11th District., February 2005 Session Official Event of 2005 WHCOA.

Shirley Darnauer

500 Pacific Avenue, #801

Virginia Beach, VA 23451-3542

Phone: 757-422-4038 (H), 757-428-4600 (W)

email: shirleydvabch@aol.com (H), shirley.d@longandfoster.com (W)

Appointed by: Congresswoman Thelma Drake (R-2nd)

Biographical Statement:

Shirley is an 18 year active Real Estate Agent with Long and Foster/Oceanfront Office in Virginia Beach, VA. She is a member of the Circle of Excellence & Lifetime L & F Gold Team Member and received Two Outstanding Service Awards from Realtor Associates. Actively working residential and senior housing needs in the 55+ retirement homes. President of Huntington County Chamber of Commerce 1980-1981. Bush/Quayle Presidential campaign 1988. Congressman Dan Coats and later Senator Dan Coats election volunteer coordinator. President, Virginia Beach Republican Women's Club 1995-1996 and Secretary, City Committee, Virginia Beach 2002-2003.

Bush/Cheney campaign volunteer.

Congressman Ed Schrock appointee to the National Silver Haired Congress 2000-2004.

Congressman Ed Schrock representative to Republican Party of VA-2nd District.

Congresswoman Thelma Drake appointee to the National Silver Haired Congress

Region 111. Vice Chairman 2004.

Attended "Solutions Forum" for WHCOA in Williamsburg, April 2005.

Shirley has a Daughter and Son-in-law living in Norfolk and a Son, daughter in law, and three Grandchildren living in Hong Kong while serving a mission that benefits orphans in China.

Patti Lee Ferguson

Eastern Oxygen and Medical Equipment, Inc.

818 Professional Place West

Chesapeake, Virginia 23320

Phone: 757-547-8188

Email: patti@easternoxygen.com

Appointed by: Congressman Randy Forbes (R-4th)

Biographical Statement:

Patti Ferguson been employed by Eastern Oxygen and Medical Equipment, Inc. since 1986. She is also a member of the Chesapeake and Suffolk Task Force on Aging. She indicates that she has gained so much knowledge over the years working with the elderly, disabled, and the disadvantaged and is gratified to know that you can make a difference in someone's life. She is very excited about being a participant in the 2005 Conference and looks forward to meeting other attendees.

Vicken V. Kalbian, MD, FACP, DTM&H (Eng)

1408 Gordon Place

Winchester, VA 22601

Phone: 540-667-8348

Email: vkalbian@adelphia.net

Appointed by: Congressman Frank Wolf (R-10th)

Biographical Statement:

Dr Kalbian is Medical Director of Valley Community Healthcare Network in Winchester. He is a retired internist and the 2002 recipient of the "Laureate Award" of the Virginia Chapter of the American College of Physicians and the American Society of Internal Medicine. He has held academic positions at Johns Hopkins University Hospital in Baltimore and Shenandoah University in Winchester, VA.

Paul J. Klaassen

7902 Westpark Drive

McLean, VA 22102

Phone: 703-744-1602

Email: paul.klaassen@sunriseseniorliving.com

Appointed by: Governor Mark Warner

Biographical Statement:

Paul Klaassen is Chairman and CEO of Sunrise Senior Living. He founded Sunrise with his wife Terry in 1981 to introduce a new resident-centered model of eldercare based loosely on Dutch assisted living models in which his grandmothers had lived. Known for its resident-centered model and award-winning architecture, Sunrise communities provide a full range of personalized senior living services. Sunrise operates 390 communities in the United States, U.K. and Canada with revenues of \$2 billion. Sunrise serves 45,000 residents with over 30,000 team members. The company went public in 1996, and is listed on the New York Stock Exchange (NYSE: SRZ). Mr. Klaassen is the founding chairman of the Assisted Living Federation of America, an industry trade group.

Vola Lawson

1111 Bayliss Drive
Alexandria VA 22302
Phone: 703-683-4091
Email: Volalawson@Comcast.Net
Appointed by: Congressman Jim Moran (D-8th)

Biographical Statement:

Vola Lawson is the retired City Manager of Alexandria, VA (1985-2000). She is the recipient of the National Award for Outstanding Public Service for both the American Society of Public Administration and National Academy for Public Service; 1997 Outstanding Public Administrator in the State of Virginia; Virginia Women's Hall of Fame; 2000 Washingtonian of the Year; 2000 Working Woman of the Year, by Channel 7, National Public Radio, and Toyota Motor Co.; Recipient of two national program excellence awards from international city/county management assn; Recipient of several community leadership awards: Urban League, Alexandria Bar Assn, Chamber of Commerce, Senior Services Committee, NAACP, and others.

Richard W. Lindsay, MD

352 Key West Drive
Charlottesville, Virginia 22911
Phone: 434-293-9769
Email: rwl31@virginia.edu
Appointed by: Governor Mark Warner

Biographical Statement:

Dr. Lindsay is the Chairman of the Commonwealth Council on Aging (Virginia's statewide aging advisory board). He is Professor Emeritus of Internal Medicine and Family Practice at the University of Virginia in Charlottesville, Virginia. He is the former Head of the Section of Geriatric Medicine at the University, a position he held from 1977 until his retirement in 1999. Dr. Lindsay served as the President of the American

Geriatrics Society in 1985-86, and then Chairman of its Board of Directors. He is also on the Board of the University of Virginia Medical Alumni Foundation.

Sandra R. Markwood

3305 Holly Street
Alexandria, Virginia 22305
Phone: 202-872-0888
Email: smarkwood@n4a.org
Appointed by: Governor Mark Warner

Biographical Statement:

Sandy Markwood is the CEO of the National Association of Area Agencies on Aging (N4A), the organization which represents the nation's Area Agencies on Aging and serves as a champion for the Title VI Native American aging programs. Prior to joining N4A, Markwood worked for 20 years at the National Association of Counties, the National League of Cities and as Assistant to the County Executive in Albemarle County, VA. In these positions, she provided policy and programmatic support to counties and cities throughout the nation on aging, health, housing, community development, land use, transportation, environmental quality, and workforce development issues.

Marilyn Pace Maxwell

MEOC
PO Box 888
Big Stone Gap, VA 24219-0888
Phone: 276-523-4202
Email: mmaxwell@meoc.org
Appointed by: Congressman Rick Boucher (D-9th)

Biographical Statement:

Executive Director for past 31 years of Mountain Empire Older Citizens, Inc., the Area Agency on Aging and Public Transit Authority for far southwest Virginia. Holds a B.S. from the University of Alabama, an M.S.W. from the University of North Carolina, Chapel Hill, and a post-graduate Specialist In Aging Certificate from the University of Michigan Institute of Gerontology. Received UNC School of Social Work's 2000 Outstanding Alumnus Award, the school's highest honor. Named Wise County's 2002 Outstanding Citizen. Serves on Governor's Commission on Alzheimer's and Related Diseases and has served as a Delegate to the two previous White House Conferences on Aging.

Ruth P. Nelson, PhD

443 Laurel Avenue
Fredericksburg, VA 22408-1571
Phone: 540-710-0786
Email: rnelson443@aol.com
Appointed by: Congresswoman Jo Ann Davis (R-1st)

Biographical Statement:

Since 2000, Dr. Nelson has served as the State President for AARP in Virginia. She earned a PhD in Higher Education Administration from Wayne State University in Detroit, MI. She grew up and resided in Detroit, MI until she retired. Her professional work life in Detroit was divided between the Detroit Public Schools and Wayne State University. After retiring, she chose Fredericksburg, Virginia as her retirement home. After retiring to Virginia, she continued her volunteer experiences that started in Detroit. She has counseled and tutored inmates at the local jail and currently tutors adults via the local adult literacy program.

Judi G. Reid

PO Box 29721
Richmond, VA 23242
Phone: 804-784-0445
FAX: 804-784-8816.
Email: Not available
Appointed by: Senator George Allen

Biographical Statement:

Judi Reid is the immediate past chair of Virginia's Commonwealth Council on Aging and former member of the Governor's Advisory Board on Aging. She began her advocacy 25 years ago as her family faced the challenges of long-distance caregiving for aging parents. She was the founder of Green Inc of Virginia, which published *Senior Lifestyles: Retirement Resource and Housing Guide*. Judi has served as a resource for a two-year legislative study of the "impact of Virginia's aging population on state agency services, policies and program management" which will be considered by the 2006 session of Virginia's General Assembly.

Katie M. Roeper

SeniorNavigator
600 E. Main Street, Suite 360,
Richmond, VA 23219
Phone: 804-827-1280
Email: kroeper@seniornavigator.com
Appointed by: Governor Mark Warner

Biographical Statement:

Katie Roeper is Executive Director of SeniorNavigator, a Virginia public-private partnership that provides health and aging information to seniors and caregivers. Recognized as a best practice by the National Governors' Association, SeniorNavigator combines a database of 19,000 local service listings with 240 SeniorNavigator Centers to help connect those in need with available services. Previously, Ms. Roeper ran a full-service marketing agency which focused on helping non-profits and government agencies develop effective communication tools. Her award-winning campaigns have

been recognized by the International Association of Business Communicators, Public Relations Society of America, and Educational Press Association of America.

Virginia Russell

2212 Rocky Point Parkway
Richmond, VA 23233
Phone: 804-740-0303
Email: varussell@webtv.net
Appointed by: Congressman Eric Cantor (R-7th)

Biographical Statement:

Virginia Russell of Richmond, VA served for 31 years as a librarian in the public schools and colleges of Virginia. She earned a BS degree from Longwood College in 1997. Ms. Russell was appointed by her congressman to the inaugural session of the National Silvered-Haired Congress (NSHC). She has represented the 7th district at all eight sessions of the NSHC and was elected Virginia State Chair in 2001. She also served for eight years on the Longwood College Board of Visitors from 1994 to 2002. She is an active volunteer in local and state government, education, and aging issues.

William Alfred Tucker

1103 Guthrie Road
Hampton, VA 23666
Phone: 757-826-1000
Email: Not available
Appointed by: Congressman Robert Scott (D-3rd)

Biographical Statement:

William A. Tucker served in the United States Navy (1943-1946) and is a retired veteran of the US Air Force (1952-1974). He is also a retired Longshoreman Local 846 and served as president from 1988-1992. In 2004, Governor Mark Warner appointed him to serve on the Professional and Occupational Regulation Board. Recently, he was appointed to the City of Hampton Board of Military Affairs Committee. He also serves on the Executive Board of the Hampton Roads Democratic Party, the VFW, and the Disabled Veterans. He has been married for 56 years and has five children and five grandchildren.

Gordon J. Walker

JABA
674 Hillsdale Drive, Suite 9
Charlottesville, VA 22901-1799
Phone: 434-817-5222
Email: gwalker@jabacares.org
Appointed by: Congressman Virgil Goode (R-5th)

Biographical Statement:

Gordon Walker has been the executive director and chief executive officer of the Jefferson Area Board for Aging (JABA) since 1982. In that capacity, he presides over all JABA operations, programs, and marketing and development activities. He is an adjunct professor in the School of Nursing at the University of Virginia, and has also served as president of several local, state, and national organizations. He is currently chairman of the Albemarle County School Board. In 1995, Gordon was appointed to the White House Conference on Aging as a representative for the State of Virginia. Prior to his tenure at JABA, he was associate director of the Georgia State University Gerontology Center, a legislative aide to the U.S. Senate Committee on Aging, and deputy director of the Vermont Department of Aging.

Alternates

The following individuals have been named as alternates to serve in the event that a delegate is unable to participate in the conference:

Governor's Alternates

Eleanor Bradshaw – Former member of the Commonwealth Council on Aging, the DMAS Policy Board, and currently active in health care in the Tidewater area and a resident of Norfolk, VA.

Elaine Byrd – Former caregiver and former member of the Alzheimer's Commission and a resident of Waynesboro, VA.

Steven Cochran - Director of human resources at HHHunt and a resident of Blacksburg, VA.

Congressional Alternates

Ellen Nau – Program Coordinator with the Virginia Department for the Aging and a resident of Richmond, VA.

John Skirven – Executive Director of Senior Services of Southeastern Virginia in Norfolk, VA.

Note: this list includes Virginia's gubernatorial and congressional appointments. Virginia's at-large delegates will be added as soon as these appointments are made public.

Updated 8/5/05

COMMONWEALTH of VIRGINIA
Department for the Aging
Jay W. DeBoer, J.D., Commissioner

MEMORANDUM

TO: Executive Directors and AAA staff,
Area Agencies on Aging

FROM: Bill Peterson,
Deputy Commissioner for Programs

DATE: August 9, 2005

SUBJECT: A Geriatrician Deals with Long-Term Care

Attached you will find an article written by a geriatrician that appeared in *Health Affairs: the Policy Journal of the Health Sphere* titled ***What Are We Going To Do With Dad?*** This is a rather long article and difficult to read (the author is a physician...not a professional writer!). However, it is well worth the time.

I would suggest that you share this article with your staff, your governing and advisory board/council members, as well as with your legislators and others in your PSA. This is an honest, moving, and thought-provoking overview of our long-term care system.

Attachment

What Are We Going To Do With Dad?

Jerald Winakur, MD

Health Affairs: The Policy Journal of the Health Sphere
Vol. 24, Issue 4, Pages 1064-1072
2005

PREFACE: America is getting older, and older Americans are living longer. What has not changed is the dysfunction and illness that usually accompany aging. Geriatrician Jerald Winakur looks at the "vast inland sea of elders" that is building and wonders where the doctors will come from to care for them. Writing as the son of an eighty-six-year-old man with dementia, Winakur also details the nitty-gritty of caring for an increasingly debilitated parent. In both of his roles—loving son and highly skilled professional—he is hard pressed to alter a course that punishes his dad and tears at his family. Even as medical science extends life, the future seen through his eyes is fraught with clinical and moral quandaries.

My father is eighty-six years old. He was never a big man, except perhaps to me when I was his little boy. At most he was five feet, eight inches tall and weighed 160 pounds. Today he weighs barely 120. Maybe he is five feet two. He teeters on spindly legs, a parched blade of grass in the wind, refusing the walker his doctor recommends or the arm extended in support by those of us who love him. He doesn't know what day it is. He sleeps most of the time, barely eats. Shaving exhausts him. His clothes hang like a scarecrow's. Getting him in for a haircut is a major ordeal. He is very deaf but won't wear his hearing aids or loses them as often as a kid might misplace his marbles. He drives my mother—five years younger—crazy to tears.

My only sibling, the architect, asks me every time we are together (which is often because we all live in the same town) and every time we speak on the phone (which is almost every day because we are a close family now in crisis): "What are we going to do with Dad?" As if there must be a definitive answer, some fix—say, putting a grab bar in the bathroom or increasing the width of the doorways.

He asks me this question not just out of fear and frustration, not only out of a realization that it is time for the adult children of a progressively demented elderly parent to act, but because he figures that his older brother who has been practicing medicine for almost thirty years should know the answer. I do not know the answer. I do not have a pat solution for my father or yours—neither as a son, a man past middle age with grown children of his own; nor as a doctor, a specialist in geriatrics, and a credentialed long-term care medical director.

In the United States today there are thirty-five million geriatric patients—over age sixty-five—and of these, 4.5 million are over age eighty-five, now characterized as the "old old." The American Medical Directors Association, the professional organization that

credentials physicians in long-term care, has certified only 1,900 doctors in the entire country. As we baby boomers go about our lives, frozen into our routines of work and family responsibilities, a vast inland sea of elders is building. By 2020 it is projected that there will be fifty-three million Americans over age sixty-five, 6.5 million of whom will be "old old." Many of you will be among them. America will be inundated with old folks, each with a unique set of circumstances: medical history and the manifestations of the particular dementing process; medication use; emotional and psychological makeup, including past traumas and present-day fears; family dynamics; support structures; and finances.

Compounding all of this is the sad and frustrating fact that our government appears to have no policy vision for long-term elder care. Our leaders seem to wish—perhaps reflecting our own collective yearnings as a vain, youth-worshipping society—that when the time comes, the elderly will take their shuffling tired selves, their drooling and incontinence, their demented ravings, their drain on family and national resources, and sprawl out on an ice floe to be carried off to a white, comforting place, never to be heard from again.

For the past nine years I have been the medical director of my hospital's skilled nursing unit, or SNU as we call it. This unit receives transfers from all areas of the acute care hospital when attending physicians feel that their patients have reached a point where they no longer need acute care services yet are unable to return home. Sometimes it is obvious what we have to do: finish out a course of intravenous antibiotics in a patient with an infected wound or provide a few more days of rehab to a competent elder who has just undergone a hip replacement. But more and more, as our patients grow older and more frail, it becomes clear that the attending physicians have requested that their patients come to the SNU because they don't know what else to do with them.

Each week I attend the SNU team care conference. Every staff professional who has a role in caring for patients on the unit attends, so around the tables pushed together in the unit's "activity room," amid the puzzles and games almost none of the patients has the ability to play, the magazines most no longer have the eyesight or insight to read, sit a registered nurse; geriatric nurse specialist; pharmacist; social worker; activity coordinator; physical, occupational, speech, and respiratory therapists; dietitian; and myself. We discuss each patient in turn and review each medication list. The nurses provide up-to-the-minute reports on medical progress or setbacks; the therapists discuss the rehabilitation status and whether the patient is proceeding toward goals set the previous week; the patient's weight and diet are reviewed; we hear about the situation at home, the help or lack thereof we can expect from family or other caretakers, and the patient's insurance and what it may or may not provide. Our main goal is to answer one major question: What are we going to do with this patient? Where can we safely send him—given his medical, social, and financial circumstances—and expect him to maintain his highest level of functioning, his remaining dignity? Very often, we don't know.

After we review each patient's case, families are encouraged to attend. Most do not—often, I think, because they are afraid we will tell them there is nothing more we can do. And they are already despondent, overwhelmed by Dad's downhill progress and the acute event that brought him to the hospital (the pneumonia, the fall, the stroke), bewildered by his deteriorating course (the mental confusion, the weakness) while there, and angered and frustrated in dealing with the bureaucracy (callous nurses, inattentive aides). Even with the attending physicians, who often drift quickly in and out on their rounds like white-coated apparitions.

So now your dad's physician—maybe the one person you thought could solve all of this, the one person you trusted (although less and less so in these days of "managed care," because it is hard to trust someone you might have just met or whose name was picked at random from a list of random names)—comes into his room and says, "I don't think there is much more we can do for him here." Your mind reels. Nothing more to do? In America? Home of the most advanced health care in the world? The land of Medicare and Web MD? You think about all the glowing seniors—continent, smiling, sexually active—in those drug ads on TV or the aging but robust movie stars on the cover of the AARP magazine. Nothing to do?! What, I'm supposed to take him home like this? You gotta be kidding, doc! And anyway, he was just fine until he came to the hospital!

The doctor sighs. She has been through this many times and still doesn't quite know how to handle it. Even though the ravages of aging are not her fault, she feels the stern gaze of Hippocrates on her back and wants to do more. She might remind you—tactfully—that this patient, your father, lying with sallow distorted face, partial paralysis, a Foley catheter now hanging out of his penis attached to a bag clipped to the bedrail, was not fine when he came to the hospital. He was not shanghaied from his home where he sat smoking his pipe and reading the *Wall Street Journal*. Rather, this man, her patient whom she doesn't know what to do with at this moment, arrived in the ER at 4 a.m. hypertensive and gurgling, brought in by ambulance after he passed out in the bathroom and hit his head on the toilet.

"I think perhaps we can transfer your father to our skilled nursing unit for some rehabilitation," the doctor says. I say it all the time. Family members are uncertain what this means except that they don't have to take Dad home just yet and are temporarily grateful. The doctor has postponed answering the "What are we going to do with Dad?" question for a while longer. Every Medicare patient has coverage for one hundred lifetime SNU days if the criteria outlined in thousands of pages of regulations are met. But past the first week or two or three, these criteria usually can no longer be satisfied—not because the patient is well; very few get well once they get to the SNU—but because the patient is "no longer making progress." The patient is caught in the downward spiral of old age, disability, and dementia.

From here there is no "progress" except toward the grave. And the next way station is chronic custodial nursing home care. Family members will soon discover, if they haven't already, this essential Medicare insurance coverage fact: There is no Medicare coverage for long-term custodial nursing home care. Unless, of course, an elderly loved

one is destitute, in which case he might qualify for some state-sponsored Medicaid assistance. And this often can be quite problematic depending on the level at which his state reimburses its long-term care facilities.

And, typical of our government, as SNUs are being used more and more (as so many medical practitioners find themselves stymied by the "what are we going to do next?" question), Medicare has cut the reimbursements to these units drastically (not limiting the benefit to the patient, of course, which might anger the consuming public), so that many are closing. My own unit shrank to half its size before being shut down by its sponsoring hospital—even as I was writing this piece. Although the CEO told me that this was done because my hospital needed more "acute care beds"—certainly true—closing the SNU coincided with the change in Medicare reimbursements to SNUs that made it financially advantageous for acute care hospitals to jettison their SNUs in favor of more acute care beds.

Thirty years ago I became a physician. My father, a first-generation American born of immigrant Russian Jews, was then the age I am now. He never completed high school. He was a sensitive man who helped his fatherless family eke out a living through the Depression and then served five years in the Army Air Corps—a member of the "Greatest Generation." He ended up a man who was neither secure nor successful, even in this country's most optimistic years. But he was proud of me, a college boy, a medical school graduate.

In my family there was no more honorable profession than medicine, and the highest calling to my generation of physicians was the discipline of internal medicine—to follow in the footsteps of Sir William Osler, an empathic bedside clinician, a skilled diagnostician of the first order. To become a physician who derives great joy from shepherding his practice, his flock of interconnected families and friends through their medical lives, available for those frightening calls in the night, those tense moments in the ER, those difficult days in the intensive care unit (ICU). The one who is trusted to help make the tough choices, the final decisions. The one true patient advocate with broad knowledge, compassion, and unbiased judgment. More than half of the graduates of my medical school class pursued a career in general internal medicine. By 2003, that career choice among all first-year residents had declined to 19 percent.

Primary care, especially geriatric primary care, is time-consuming, excruciatingly detail-oriented professional piecework—all of those visits, those slowly moving, wheelchair-bound, unsteady elders to get onto and off of examination tables. Their pencil-scrawled complaints and medication lists to decipher, to question, to strip down, remake, and remodel at every encounter—a tiny dosage change here, an elimination or substitution there—all the time wondering: what am I missing? What else can I do? Not many young doctors want to preside over this carnage of human obsolescence or be reminded every working day of their own inevitable slide into disability and dementia.

In this work, the arenas change but not the inevitabilities: hospitals after the falls and broken hips; ICUs after the inevitable cascading complications of postoperative strokes,

infections, and embolisms. Then the SNU and rehabilitation hospital admissions and, finally, custodial nursing homes. The patients become less responsive, less the people they used to be; their families become more uncertain, more demanding, more shrill from half a continent away. They call, fax, e-mail, wanting details, updates, help, answers. Visit by visit I document declines. After a lifetime of practice, I find myself presiding over legions of chronically ill people—my extended family now—and every week there is another death certificate to sign, another condolence card to send, another funeral to attend.

There are many sexy career choices in medicine today, all the highly paid specialties and their procedures that actually—if all goes well—restore functioning and stave off death and disability, at least for a while. Snap in new knees or hips or shoulders. Laser the grunge out of blocked coronaries. Snip out the polyps that might become cancers. Suck out the fat, prop up the sags, botox the wrinkles, burn up the spider veins, pop in the new lenses, pump up the withered penis. Resolve the problem at hand, pocket the Medicare payment (or, even better, collect the full retail fee from "uncovered" procedures from your well-heeled patients), tell yourself what a great physician you are, and send your satisfied medical consumers back to their "primary geriatrician" quickly—before they fall, seize, stroke, and become incontinent on the plush-pile carpet of your waiting room.

Three years ago my father, a longtime heart patient, had trouble breathing and complained of chest pain. He was admitted into the hospital with congestive heart failure. This is the hospital in which I have made rounds almost every day for the past three decades. Many of the nurses and therapists and I call each other by our first names. The CEO is my friend and patient. My father's physician is one of my young associates, well-trained and eager. I was confident that my father would receive the best medical care he could get in America today. Yet I would not leave him alone in his hospital room. During the day, if I or my brother or mother could not be there, I had a hired sitter by his bed.

It's rarely talked about, but acute hospitalizations are the most dangerous times for the elderly. Even if they have never before manifested any signs of confusion or disorientation, it is in the hospital—in a new and strange and threatening environment, under the influence of anesthetics, pain pills, anti-emetics, and soporifics—where the elderly (competent or not) will meet their match. Add to this the iatrogenic mishaps (caused by the "normally expected" side effects and complications of standard medical procedures) and the human errors (mistakes in drug dosing, the right medication given to the wrong patient)—now multiplying in our modern hospitals like germs in a Petri dish—and it is almost a miracle that any elderly patient gets out of the hospital today relatively unscathed.

I stayed with my father every night; I slept in the reclining chair by his bed. I got up when he did; ran interference with bedrails, side tables, and IV poles; guarded his every move to the bathroom; looked at every medication that was handed to him and every fluid-filled bag plugged into his arm. I was not afraid to question the nurse or even call

his physician. Each day my father descended deeper and deeper into paranoid confusion. He couldn't rest, he was intermittently unsure of who I was. At first I could calm him with my voice, talking about the old days, reminding him of our fishing trips on the Chesapeake Bay when I was young. Then he needed the physical reassurance of my hand on his arm or shoulder at all times. Finally, so that he could get some rest, I got in the bed with him and held him, comforting him as he once—in a long-ago life—did for me.

After four days and nights in the hospital, I knew I had to get my father out of there. His doctor came by and told me that his heart failure was better and that his dementia evaluation did not show a treatable or reversible cause. But he didn't like the way my father looked—he was agitated and sleep-deprived and deconditioned, a perfect candidate for some time in the SNU. And, after all, here I was, his senior associate, the medical director of the SNU. Surely my dad would get good care there.

I took my father home. I knew if I didn't get him home at that moment, he would never come home again. The SNU for my dad would have been only a way station to a custodial nursing home. I arranged for a home health agency to come to my parents' house and provide my father with physical therapy to aid in his reconditioning and to assist with his bathing and dressing and grooming—something Medicare covers, but for only a limited period. I went to the pharmacy and filled the eight prescriptions he left the hospital with, and I went back again to buy the blue plastic container divided into daily dosing compartments when I realized that my mother was having trouble reading the labels on the bottles and following the instructions. How long had this been going on?

When I visit my father these days, if he is not asleep, I sit down beside him on the couch and talk at high volume into his hearing aid, if he has remembered it. Our conversations go something like this:

"How are you feeling today, Dad?"

"Not so good. You ought to come around more often."

"Dad, I was just here yesterday."

"Why are you calling me that? You're not my son."

"Of course I'm your son. That's your wife, my mother, sitting over there." (My mother: "What are you saying?! Of course he's your son!")

"I like you and all, but you're not my son."

"Well, I love you anyway."

"You're older than I am. How could you be my son?"

"I love you, Dad."

"You ought to come around more often."

(My mother: "See what I'm putting up with all the time?")

Yet through the fog of his senility I still recognize my father, and once in a while he will surprise me. "Remember those big rockfish we used to catch off Thomas Point Light?" he might say. And then nothing.

The Medicare coverage for the home health care ran out almost as soon as it began. Between my brother and me, one of us is there almost every day. We have been fortunate to find two dedicated women to help my mother attend to my father's daily personal needs. My brother and I help with the cost of this—\$1,500 a month, but still only one-third of the cost of custodial nursing home care. I often wonder: Why isn't this kind of care covered by Medicare or Medicaid? After all, when my parents use up their meager savings (which they will), like most families with a demented elder, they will become eligible for Medicaid, and the state will then pay the entire cost of custodial nursing home care. But the longer we can keep my father at home attended by aides, the cheaper his long-term care cost will be to society as a whole.

Drinking the supplemental nutritional feedings my brother brings to the house by the case (another non-covered cost of several hundred dollars a month), my father has actually put on a few pounds. I keep his medicines stocked, and I fiddle with the doses now and then, a tad extra diuretic when I see he is more short of breath, a tiny dose of an antipsychotic when he becomes more agitated. We get him in to see his doctor regularly for follow-up examinations and laboratory testing. And still, every week he gets worse, harder to deal with, more bizarre.

Recently, he has begun to holler at my mother every time she tries to help him change his clothes, which is often because he wets himself. "You're my sister! You're not supposed to see me naked!" he screams at her. He can no longer find his way from the living room to his bedroom in their tiny one-story house.

Most of us do not recognize when the mental capacities of our spouses or parents are reduced until something happens, something unexpected. My mother just didn't get it that my father was demented; she continued to believe his stubbornness and withdrawal were purposeful acts of belligerence against her. Until the day she realized he could no longer figure out how to unlock the front door by himself, she continued to blame him for his disability. Adult children are often no different in their lack of insight; we expect our parents, after all, to be our parents. Dad is just being cold and distant because he's still angry over something from years before, a son might believe. The sad fact is that Dad forgot about this incident long, long ago.

From my years as a geriatrician and now as the son of an "old old" man, I recognize that there is but one inescapable truth: Our parents will become our children if they live

long enough. Perhaps if we looked on our elderly in this way, we would be kinder to them. They will become dependent on us, our stronger arms, our acts of gentleness and caring. We will arrange for their meals, pay their bills, take them to their doctor visits, sit by their bedsides at the hospital and in the nursing home.

I don't know what else to do for Dad at this moment, but I know what is likely to happen to him if he does not die in his sleep, a heaven-sent coup de grâce that from long experience I recognize is unlikely to occur. There is almost always a great struggle in the end. One day I will get a frantic call from my mother that he is on the floor and she cannot get him up and he is crying out in terrible pain. Wherever I am, I will drop what I am doing and race over there and find that one of his legs is shortened and externally rotated. His hip is broken. From the wall phone in my parents' kitchen, I will call my brother and I will tell him all the reasons why we should not send him to the hospital: He might not recover from the surgery—indeed, might die on the table given his bad heart. But even if he does survive, he will spend days in the ICU, probably on a respirator, until his heart is stable. And then he will be constantly confused and agitated. I don't see him ever being able to cooperate with physical therapy. At best he will end up in a nursing home, bedridden and at the mercy of overworked, underpaid aides. He will descend deeper and deeper into disorientation and delusion, require medications to keep him from harming himself, and die anyway in a few months—or perhaps even a year or two if he is unfortunate and the care is better than average.

My brother will hear my mother crying and my father hollering in the background. He will feel guilty that he is not in the house with me at that moment. He will remember the time our father took us on a summer vacation to the White Face Mountains and we all huddled together on the swinging bridge in the mist, as the Ausable River tumbled and roared through High Falls Gorge. Then he will say, "Maybe it won't be as bad as you think. Maybe we can set up a hospital bed in his room—I think the door is wide enough—and it won't take much to alter the shower to accommodate a wheelchair." There will be a moment of silence. "I don't know," he'll say. "You're the doctor. What do you think we should do?"

I do not tell him that I often, in fitful sleep, dream that when the time comes I go to my father's bedside, quietly fill a syringe with morphine, and stroke his arm as I place the tourniquet. I tell him over and over again how much I love him and what a good father he has been to me as I slip the needle into his antecubital vein. Then I say how much I will miss him and goodbye, Dad, goodbye, as I push the contents into his blood stream. In this dream I tell my mother and my brother that he has gone peacefully in his sleep.

Yet I have not until now given voice to this dream because I know for certain that in the end, I could never do this. Not to my poor, demented, suffering father. Not to anyone. I know there are some who disagree with me, and perhaps this is one way our society will ultimately deal with its flood of elders in this age of limits. I will by then, I hope, be old and no longer on the front lines. When my time comes—before it comes—I will choose for myself. But for now, as long as I have the will and the strength to practice, I

am a physician deeply steeped and firmly rooted in the art and tradition of healing, of comforting.

For my father, on that day, I will tell my brother that I will handle it and hang up the phone. Then I'll pick it up again and dial 911.